# commitment into ACTION

Recommendations of the Delaware Advisory Council on Cancer Incidence and Mortality We dedicate this report to all those who have shared their stories—both triumphs and tragedies—with us.

Your indomitable spirit inspires us to seek answers and affect change.



# A Special Thank You

#### To our guest speakers:

We would like to express our appreciation to the following individuals who shared their stories with us. Your courage, spirit and drive to make a difference inspire us all:

Sterlin Beckwith
Brenda Billingsley
Jerry Broussard
Nellie Foster
Judy Leiberman
Shirley Moore
Mary Ellen Nantais
Rebecca Wolhar

To all the public attendees who shared their interest and insight.

To the presenters during council or subcommittee meetings who guided us with their experience and knowledge:

Jon Kerner, Ph.D., National Cancer Institute Paul Silverman, Dr. P.H., Delaware Division of Public Health Lance Wallace, Ph.D.,

Research Triangle Institute

## To our nearly 200 participants in the Concept Mapping Project:

Thank you to all the people around Delaware—including survivors, family members who lost loved ones, professionals and scientists. Your ideas on cancer issues were invaluable. Your input helped lay the groundwork for our recommendations.

"...Justin is gone but my promise to him rings in my ears, to find the answers to the questions he never wanted another parent to have to ask—'why did my child get cancer

MARY FLIEN NANTAIS OF NEWARK WHOSE SON, JUSTIN

and why did he have to die?"

Mary Ellen Nantais of Newark whose son, Justin, died of Cancer in 2000 at age 19.



## Inspiration to seek answers and develop a plan is all around us.

This is a report from the Delaware Advisory Council on Cancer Incidence and Mortality. It is much more than statistics and data. It represents the observations of our families, friends and neighbors whose lives have been touched by cancer. Their stories are part of our report to you. Some fought bravely and lost. Others have persevered and learned the meaning of the word courage. They represent the reason why our Council was formed by Governor Minner and the Delaware General Assembly in March 2001.

## Our goal is obvious—to find methods to reduce cancer in our state.

We culled information from every area—from many experts—from any who would volunteer their personal experiences. We talked to more than 195 people who are living with the disease or have experienced its devastation. We coordinated brainstorming sessions. We solicited over 500 thoughts about the disease. We identified 118 solid ideas about controlling cancer in Delaware.

## Our results—and a workable plan—are here for you to see.

A clear set of priorities was established by the Council. Six subcommittees got to work identifying recommendations. The work was reviewed and is here in this report. It's just a beginning. But it's our hope for the future.

## **BACKGROUND**

## Formation of the Advisory Council on Cancer Incidence and Mortality

The Delaware Advisory Council on Cancer Incidence and Mortality was formed in March 2001 in response to Senate Joint Resolution 2 (Appendix ???) signed by Governor Ruth Ann Minner. The Advisory Council, consisting of 15 members appointed by the Governor, was established to advise the Governor and Legislature on the causes of cancer incidence and mortality and potential methods for reducing both.

#### **Developing a Plan for Action**

The Advisory Council on Cancer Incidence and Mortality began meeting in April 2001 with the shared understanding that their work would be focused on developing a clear and usable cancer control plan. Another shared priority was that extensive input would be needed from professionals in cancer control, as well as from Delaware citizens affected by cancer. With these priorities in mind, Advisory Council worked on a system to:

- create a shared awareness and agreement on the range of cancer control issues to be addressed now and in the future:
- create a structure and agenda for addressing these needs;
- enable Delaware to move forward with meaningful action for its citizens

To accomplish these goals, the Advisory Council heard from speakers on Delaware cancer statistics, including Dr. Jon Kerner from the National Cancer Institute, and began monthly presentations from Delaware cancer survivors or family members who had lost a loved one to cancer. The stories,

woven throughout this report, provided valuable insight into some of the concerns and barriers faced by people battling cancer, the stress this disease places on all aspects of their lives, and ideas for ways that Delaware can help ease these burdens on its citizens.

A unique project, called Concept Mapping, was also initiated to get input on cancer issues from Delaware citizens and to help the Advisory Council establish priorities and its scope of work. The Advisory Council invited more than 195 Delaware citizens who are invested in cancer control efforts to participate in the project. Both the Advisory Council and those invited, completed the Brainstorming phase, during which they provided their ideas on completing the statement: "A specific issue that needs to be addressed in comprehensive cancer control in Delaware is...." Over 500 statements were submitted and editing of these to avoid duplication resulted in 118 ideas about controlling cancer in Delaware. These ideas were then rated, relative to each other, on importance and feasibility.

## Development of Subcommittees and Recommendations

From the results of the Concept Mapping activity and the numerous speakers, the Advisory Council developed a clear set of priorities and established six subcommittees to address these issues. Each subcommittee, chaired by a member of the Advisory Council, was provided with a list of priorities in its focus area, from which specific recommendations were developed. The Advisory Council carefully reviewed the work of the subcommittees, made modifications or additions as needed, and the resulting final recommendations are compiled in this report.

EXECUTIVE SUMMARY

#### WHY IS CANCER IN DELAWARE SO IMPORTANT?

Cancer is always life changing for the people diagnosed, their families and loved ones. Cancer is the second leading cause of death in Delaware and every one of us is at risk for developing this dreaded disease. The cancer issues in Delaware are not new and they belong to each of us. The fact that so many of us are affected makes the need for meaningful action much more urgent.

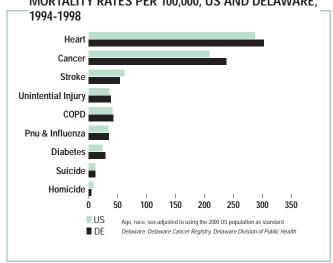
#### How much Cancer is there in Delaware?

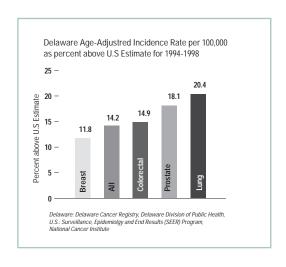
In 1999, 3786 Delawareans were diagnosed with cancer. 1735 died.

Delaware's cancer rates are higher than the national average. This is true both for incidence (number of people diagnosed with cancer) and death rates. Cancer incidence rates peaked in Delaware and the

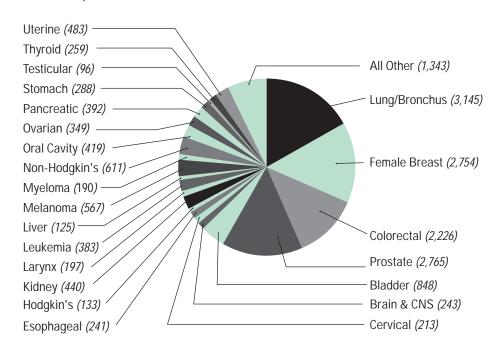
nation in the early 1990's. Since then, rates have begun to decrease. Between 1994 and 1998, the cancer incidence rate in Delaware was 10% above the national average.

## 5-YEAR AVERAGE AGE, RACE, SEX ADJUSTED MORTALITY RATES PER 100,000, US AND DELAWARE,





## CANCER BY TYPE (NUMBER OF CASES), DELAWARE, 1995-1999



#### WHAT CAN BE DONE?

The reality is that cancer is a complex disease. We do not know all of the answers, but we have a wealth of information that can make a tremendous difference. If we commit to the recommendations in this report, here's what we can do:

#### **Immediately**

- Improve the quality of cancer care in Delaware and help people with cancer get the services they need
- Increase screening so that cancer is diagnosed earlier
- Pay for cancer treatment for the uninsured

#### Over the long term

- Decrease cancer incidence rates
- Decrease cancer death rates
- Make Delaware a model for quality cancer care and early detection
- Eliminate the differences in cancer rates between different races, genders and socioeconomic groups
- · Learn more about who gets cancer and why

## RECOMMENDATIONS OF THE DELAWARE ADVISORY COUNCIL ON CANCER INCIDENCE AND MORTALITY

This report contains 26 specific recommendations to lessen the cancer burden in Delaware. These recommendations are grouped into the following categories:

- Increase screening for and early detection of colorectal cancer
- Provide the highest quality of care for every Delawarean with cancer
- Pay for cancer treatment for the uninsured
- Provide reliable and useable cancer information
- Reduce the threat of cancer from the environment
- Increase our knowledge about cancer including environmental causes
- Reduce tobacco use and exposure
- Eliminate the unequal cancer burden affecting minorities and the poor

#### How much will it cost?

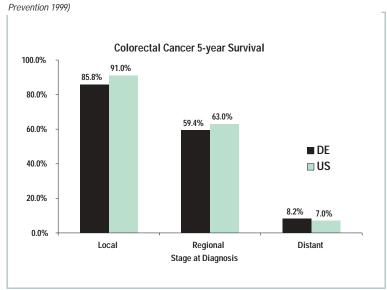
If fully adopted, our recommendations would cost approximately \$48.4 million over four years. The Council also advocates a \$0.50 increase in the tobacco excise tax and legislation allocating a portion of these funds to pay that cost, preferably designated to the Delaware Health Fund. In addition to funding all of our recommendations, this increase would result in 4200 fewer Delaware children smoking, 1300 Delaware children saved from a smoking death as an adult, and \$83.4 million dollars saved in long-term health care costs. (Campaign for Tobacco/Free Kids 2001))

## INCREASE SCREENING FOR AND EARLY DETECTION OF COLORECTAL CANCER

Colorectal cancer kills 170 Delawareans every year. Colorectal cancer can be cured if found early enough and is preventable in many cases. Unlike many other cancers, there are reliable and cost effective tests for colorectal cancer that find it early. Yet tragically, too few Delawareans know about and take advantage of this life-saving test.

### COLORECTAL CANCER 5-YEAR SURVIVAL RATES BY STAGE OF DIAGNOSIS, US AND DELAWARE, 1994-1998

(Delaware Cancer Registry, Delaware Division of Public Health; Centers for Disease Control and Provention 1999)



## ARE SOME OF US MORE LIKELY TO BE AFFECTED BY THIS THAN OTHERS?

In 1999, percent of Delawareans reporting ever having a colorectal cancer screening:

White: 45.3%Black: 39.6%Hispanic: 19.0%

Rates of death due to colorectal cancer in Delaware were 59% higher among blacks than among whites.

(Behavioral Risk Factor Surveillance Survey 1999; Delaware Cancer Registry)



"I had none of the risk factors for colon cancer and no known family history of the disease. At age 49, I awoke from surgery with a diagnosis of stage 4 colon cancer, with metastases to the lymph nodes and liver. Delaware family doctors must learn to take the symptoms of colorectal cancer seriously, and in the case of women, gynecologists need to recommend colonoscopy as a standard screening method. High standards of colorectal cancer care and monitoring should be available to all patients and health insurance companies and employers would do well to offer the highest standards of screening. Emotional support is just as important as the latest clinical advances."

| Brenda Billingsley, Wilmington.

#### WHAT CAN BE DONE?

- Screen 80% of Delawareans over 50 years of age in the next 5 years.
- Create a comprehensive statewide colorectal cancer screening and advocacy program.
- Reimburse for colorectal cancer screening of uninsured Delawareans age 50 and older.
- Case manage every Delawarean with an abnormal colorectal cancer screening test.

**WHAT IF** 80% of Delawareans age 50 and older received a colonoscopy and appropriate follow-up every 10 years...

**THEN** Delaware would have the lowest colorectal cancer death rate in the country, decreasing by more than 60%. (National Center for Health Statistics; Ranshohoff and Sandler 2002; Colditz, 2000)

**THEN** the gap in death rates between whites and minorities in Delaware would begin to close.

## PROVIDE THE HIGHEST QUALITY OF CARE FOR EVERY DELAWAREAN DIAGNOSED WITH CANCER

#### WHY?

The Council heard testimony from people with cancer. Their compelling stories detailed frustration with the over-whelming and fragmented health care system. A team approach that guides us on all levels, medically, emotionally and financially, can ease the burden and help us make informed choices. Every Delawarean also has the right to high-quality, compassionate health care that follows the latest cancer screening recommendations and treatment options. The difference can be a cancer found early and cured rather than one where delayed treatment leads to the cancer spreading and increasing the chance of death.

- Some Cancer Centers in the United States are taking a team approach to cancer care. In addition
  to oncologists and surgeons, the teams often include professionals like oncology nurses, case managers, social workers and dieticians.
- More than 600 cancer-related services are available throughout Delaware. The reality is many barriers hinder access to these resources. A case manager for every cancer patient would link patients and resources.
- Many Delawareans are already getting routine checkups. These visits must be used to encourage
  routine cancer screenings and promote prevention. A comprehensive evaluation of cancer screening practices will increase early detection.

Percent of Delawareans who have visited a doctor in the past year for a routine checkup

Age 45-54: 70.2% Age 55-64: 86.2%

(Behavioral Risk Factor Surveillance Survey 2000)

On average, the cost of care in the first six months of treatment is 33% less when cancers are
found in the early stage (in situ) instead of the late stage (distant). (Eddy 1990; Taplin, Barlow et al. 1995;
Penberthy, Retchin et al. 1999)

## ARE SOME OF US MORE LIKELY TO BE AFFECTED BY THIS THAN OTHERS?

• The rate at which people die from cancer in Delaware is consistently higher than the nation. This gap in cancer deaths can be attributed to the type of cancers, lack of screening and the need for improved access to state of the art care.



"After a pelvic sonogram, my internist and a radiologist showed me 20 tumors in my abdomen. I waited a week to be scheduled for surgery and another month for the procedure to take place. This was after I had had a complete physical three months before and was told I was in fine health. In Delaware, we need to update our diagnostic tools and recommend them to a patient, talk directly to the patient and educate them about alternatives. Sensitivity training should start at the front door."

REBECCA WOLHAR, WILMINGTON.

#### WHAT CAN BE DONE?

The Council recognizes that quality of care issues in all levels of cancer care must be addressed on an on-going basis and the recommendations that follow are first steps. It is the recommendation of the Advisory Council that the Permanent Council (see Implementation of Recommendations, page 62) have a Medical Committee, led by oncologists, to oversee implementation of these and future recommendations to make Delaware a model for cancer care. The committee will require administrative support and should include professionals in a range of disciplines addressing cancer care such as pediatrics, surgery, dietetics, palliative care and social work.

- Provide a care coordinator that is part of a statewide-integrated system to every person diagnosed with cancer in Delaware. Care coordinators will be culturally competent to overcome the language, ethnicity and gender barriers.
- Assure insurance coverage for state of the art cancer clinical trials.
- Institute centralized credentialing reviews of medical practices by third party payors that includes cancer screening, prevention, early detection and treatment practices as well as ongoing provider education.
- Support training for physicians and other health care providers in symptom management and end of life care approaches.

**WHAT IF** every person diagnosed with cancer in Delaware had a qualified case manager to make sure they had access to all the services they needed...

**THEN** differences in the death rates between whites and minorities would decline

**THEN** many barriers to care could be eliminated

**THEN** the quality of life for people with cancer would be better

**THEN** treatment outcomes would improve

WHAT IF physicians improved their cancer screening practices...

**THEN** cancer screening rates would increase

**THEN** follow-up on abnormal results would improve

THEN cancers would be diagnosed and treated earlier

**THEN** cancer death rates would decrease

# PAY FOR CANCER TREATMENT FOR THE UNINSURED WHY?

We know that people who are uninsured often wait to get medical care. We also know that the later a cancer is found, the more difficult it can be to treat. If someone you love is diagnosed with cancer tomororw, the last thing you should have to worry about is how to pay for medical care.

- 275 Delawareans without health insurance will be diagnosed with cancer this year. (Delaware Cancer Registry, Delaware Division of Public Health; University of Delaware's Center for Applied Demography and Survey Research 1994-1998)
- The Average Cost Of The First Year Of Cancer Treatment

Type of Cancer	Stage of Diagnosis	Avg Cost for First Year of Treatment
Colorectal	Local	\$34,362
Colorectal	Distant	\$40,670
Breast	Local	\$20,348
Breast	Distant	\$34,396
Cervical	Local	\$30,304
Cervical	Distant	\$48,560

(Eddy 1990; Taplin, Barlow et al. 1995; Penberthy, Retchin et al. 1999)



"I was in the Screening for Life program. They paid for my mammogram and biopsy but nothing else. My radiation bill alone was \$10,000. It's like once you have cancer, they'll tell you you have it and then you're on your own. My husband also has cancer. I'm on disability and he's on social security. There's just no extra money for medical bills. This has been a financial tragedy for us. I don't know what we're going to do."

Shirley Moore, Wilmington.

#### WHAT CAN BE DONE?

• Reimburse the cost of cancer treatment for every uninsured Delawarean diagnosed with cancer up until one year after diagnosis.

# PROVIDE RELIABLE AND USEABLE CANCER INFORMATION

#### WHY?

Cancer is a complex disease. New information about causes, early detection and treatment is available to us every day. We need to have reliable and useful information in order to make healthy choices. The decisions we make today will affect Delaware's cancer rates in the future.

## ARE SOME OF US MORE LIKELY TO BE AFFECTED BY THIS THAN OTHERS?

Minority populations are less likely to get routine cancer screening tests. As education and income levels decrease, cancer screening rates also decrease. Cancer-related public education is inadequate to ensure individuals are able to make informed lifestyle and cancer care decisions. Education efforts must be carefully targeted to communities where cancer prevention can make the most difference.

#### PROPORTION OF DIFFERENT GROUPS EVER SCREENED FOR CANCER

(Center on an Aging Society, 2000)

	Prostate Cancer		Breast Cancer	Cervical Cancer		Colore Cance		Skin Cancer
	Men 50+	Women 40	)+	Women 40+	Adults 50+			All Adults
Screening Service	Exam (%)	Exam (%)	Mammogram (%)	Pap Test (%)	Blood Stool Test (%)	Digital Rectal Exam (%)	Proctoscopic Exam (%)	Exam (%)
ALL GENDER	84	87	80	91	48	57	36	21
Male	_	_	_	_	48	63	41	20
Female	_	_	_	_	48	52	32	22
RACE								
White	86	88	81	92	49	59	37	23
Black	80	83	75	90	40	48	28	11
INCOME								
\$20,000	80	79	71	86	42	49	30	16
\$55,000	88	94	88	96	56	65	42	27
RESIDENCE								
Urban	86	87	81	91	50	58	37	22
Rural	78	86	78	92	42	54	33	19
MARITAL STATUS								
Married	86	89	82	94	50	61	38	23
Not Married	80	83	76	88	44	51	32	18



"I put off having my annual mammogram because we didn't have insurance at the time. I was persuaded to get one through Screening for Life. I was just two months late for it, but it showed a mass in my breast that turned out to be cancer. If I had not had the mammogram, it would've probably been too late for me. It was an aggressive tumor."

Nellie Foster, Dover.

#### WHAT CAN BE DONE?

- Initiate and support statewide and district-level school health coordinating councils. The statewide council will serve as a model, resource and funding vehicle for the district councils.
- Form a statewide, permanent alliance to coordinate and promote public education on cancer.
- We need to decrease our exposure to cancer causing chemicals or substances.REDUCE THE

## REDUCE THE THREAT OF CANCER FROM THE ENVIRONMENT

#### WHY?

Exposures to cancer causing substances can occur anywhere in our daily environments including our home, our workplace, during our commutes, the buildings we enter and where we spend time outside. If we know more about our environment, we can make healthy decisions and good policies. To guide us, it is also important that we collect data to have a better understanding of environmental links to cancer.

"Justin was diagnosed with a malignant brain tumor in July of 1998, four weeks before he was to start his freshman year at Penn State. He died two years later. It seemed as though I was holding my infant son once again as I looked down at his face and half closed eyes. I made a promise to him that we would find out what caused his cancer. That promise rings in my ears...to find the answers to questions he never wanted another parent to have to ask. Why did my child get cancer and why did

MARY ELLEN NANTAIS OF NEWARK WHOSE SON, JUSTIN, DIED OF CANCER IN 2000 AT AGE 19.



#### WHAT CAN BE DONE?

The Council recognizes that carcinogens can be present in the air we breathe, the water we drink, the food we eat, things that touch our skin and many other places. The decision to address the following issues on a limited basis was based on the amount of reliable information that is available and the potential to affect a change in exposure levels. It is the recommendation of the Advisory Council that the Permanent Council have an environment committee to oversee implementation of these recommendations and that carcinogens from water, food and other sources be included in future recommendations on a more comprehensive basis.

- Reduce exposures to carcinogenic substances in the ambient environment.
- Coordinate with federal OSHA to reduce workplace carcinogenic risk and exposure.
- Reduce exposure to carcinogens in the indoor environment.

## INCREASE OUR KNOWLEDGE ABOUT CANCER INCLUDING ENVIRONMENTAL CAUSES

#### WHY?

If we are to make sound decisions about controlling cancer in Delaware we must have reliable and complete information. Data can tell us about what we are doing well and where improvements are necessary. Even though we are a state with one of the most complete cancer registries in the nation, there are still improvements to be made. Collecting data is only the beginning—it is meaningless if we don't use it to target our efforts and use information to make real and lasting change.

## ARE SOME OF US MORE LIKELY TO BE AFFECTED BY THIS THAN OTHERS?

Without data and infomration, there would be no way of demonstrating that there are some of us more affected by cancer than others. While we often think of these differences in term sof race and ethnicity, we also know that a heavier burden fals on those of us with lower incomes, less education and no health insurance.



"As a colon cancer survivor, I know firsthand that improved standards are needed. In my case, a large tumor in the cecum was not detected by colonoscopic exam."

Jerry Broussard, Wilmington, colon cancer survivor.

#### WHAT CAN BE DONE?

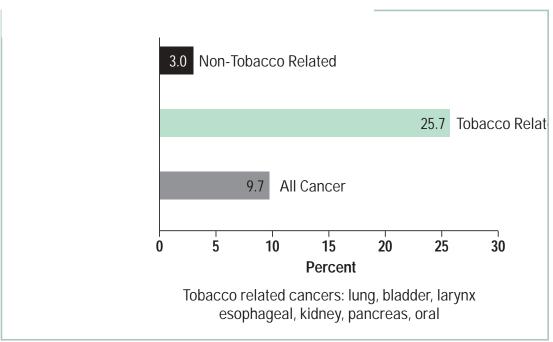
- Estimate the number of cancers that can be prevented and the number of deaths that can be avoided by primary prevention and early detection. Prioritize our common and preventable cancers.
- Improve the collection and reporting of cancer incidence and mortality data.
- Conduct a survey to examine the importance of past exposures to today's cancer rates.

#### REDUCE TOBACCO USE AND EXPOSURE

#### WHY?

Tobacco related cancers account for more than one third of all the cancers in Delaware. Delawareans smoke at a higher rate than people in 22 other states. Tobacco smoke affects smokers and non-smokers and cancer is only one of many health problems caused by tobacco. Delaware has recently increased its tobacco control spending by more than five times, but there are still actions we can take that will help protect us from the effects of tobacco.

#### PERCENTAGE INCREASE OF DELAWARE CANCER AGE-ADJUSTED INCIDENCE VS. U.S. ESTIMATE, 1994-1998



Delaware: Delaware Cancer Registry, Delaware Division of Public Health; U.S.: Surveillance, Epidemiology and End Results (SEER) Program, National Cancer Institute.)

- If not for lung cancer, the overall cancer death rate in the United States would have declined by 14% since 1950. Instead, it has increased 22%. (Surveillance, Epidemiology and End Results (SEER) Program, National Cancer Institute.)
- The death rate from lung cancer has increased only slightly overall, but is increasing more rapidly among women. In recent years, lung has surpassed breast as the leading cause of cancer death among women. (National Center for Health Statistics)
- Delaware has the 32nd lowest cigarette tax in the nation. (Campaign for Tobacco-Free Kids 2001)



"I smoked for 40 years or more. I never had any problems. Then last May, I had a pain in my shoulder. When my doctor told me to have it X-rayed, they discovered a spot on my lung. It was a total shock. They took a piece of my lung in July." | Sterlin Beckwith, Georgetown.

#### WHAT CAN BE DONE?

- At a minimum, fund comprehensive statewide tobacco control activities at \$8.6 million (CDC recommended minimum.).
- Strengthen, expand and enforce Delaware's Clean Indoor air Act to include public places and workspace environments.
- Strongly endorse, coordinate and implement the action plan recommendations presented in "A Plan for A Tobacco Free Delaware".
- Expand and sustain a comprehensive public awareness campaign on the health risks of tobacco use and support resources available to help quit smoking..
- Increase the Dealware excise tax on tobacco products to \$0.74 and seek to identify other potential funding sources to support tobacco and cancer control efforts..
- Catalog all tobacco control activites in Delaware and develop and disseminate a comprehensive public resource guide..

**WHAT IF** 30 years ago, no one in Delaware smoked...

**THEN** instead of our lung cancer incidence rate today being 10% above national estimate, it would be 12% below the national estimate. (Delaware Cancer Registry, Department of Public Health; Surveillance, Epidemiology and End Resutls (SEER Program).

WHAT IF Delaware's excise tax were increased by \$0.50 per pack...

#### **THEN**

- 4,200 fewer Delaware kids would start smoking
- 1,300 Delaware kids would be saved from a smoking death as an adult
- 4,000 fewer Delaware adults would smoke
- \$83.4 million in long-term health care costs would be saved
- \$49 dollars each year in revenue would be generated (Source: Campaign for Tobacco Free Kids, 2001)



"The recommendations of this Council will be a powerful force for change. We know what needs to be done, who should do it and where we go from here. Delaware has the opportunity to take action and make positive changes in the lives of all its citizens." William W. Bowser, Esquire, of Wilmington,

WILLIAM W. BOWSER, ESQUIRE, OF WILMINGTON, DE, COUNCIL CHAIR WHOSE SON, MICHAEL, IS A LEUKEMIA SURVIVOR.







"I had none of the risk factors for colon cancer and no known family history of the disease. At age 49, I awoke from surgery with a diagnosis of stage IV colon cancer, with metastases to the lymph nodes and liver. Delaware family doctors must learn to take the symptoms of colorectal cancer seriously, and in the case of women, gynecologists need to recommend colonoscopy as a standard screening method. High standards of colorectal cancer care and monitoring should be available to all patients and health insurance companies and employers would do well to offer the highest standards of screening. Emotional support is just as important as the latest clinical advances." | Brenda Billingsley, Wilmington.

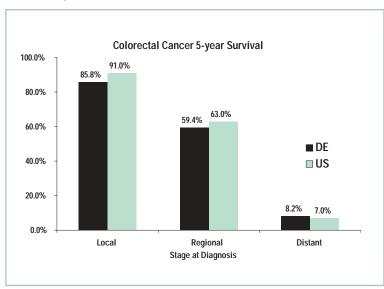


## INCREASE SCREENING FOR AND EARLY DETECTION OF COLORECTAL CANCER

Colorectal cancer kills 170 Delawareans every year. Colorectal cancer can be cured if found early enough and is preventable in many cases. Unlike many other cancers, there are reliable and cost effective tests for colorectal cancer that find it early. Yet tragically, too few Delawareans know about and take advantage of this life-saving test.

## COLORECTAL CANCER 5-YEAR SURVIVAL RATES BY STAGE OF DIAGNOSIS, US AND DELAWARE, 1994-1998

(Delaware Cancer Registry, Delaware Division of Public Health; Centers for Disease Control and Prevention 1999)



## ARE SOME OF US MORE LIKELY TO BE AFFECTED BY THIS THAN OTHERS?

In 1999, percent of Delawareans reporting ever having a colorectal cancer screening:

White: 45.3%Black: 39.6%Hispanic: 19.0%

Rates of death due to colorectal cancer in Delaware were 59% higher among blacks than among whites.

(Behavioral Risk Factor Surveillance Survey 1999; Delaware Cancer Registry)

#### Create a comprehensive statewide colorectal cancer screening and advocacy program.

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Outreach to the six major health systems (Nanticoke, Beebe, BayHealth, Christiana Care, Veterans Hospital and St. Francis) to participate in a comprehensive, community focused colorectal cancer screening and advocacy program (may be Request For Proposal.)	Delaware Healthcare Association, DHSS	Year 1	None	
2. Develop an evaluation plan	DHSS	Year 1 and ongoing	\$50,000	Delaware Health Fund, Proposed tobacco excise tax, existing resources
3. Hire project screening advocates	Health systems	Year 2	\$250,000 annually	Same as above
4. Market project and services	DHSS, Health systems	Year 2 and ongoing	\$100,000	Same as above
5. Project start up	All	Year 2	\$125,000	Same as above
6. Operational support	DHSS	Year 1 and ongoing	\$25,000 annually	Same as above

#### Points to note:

- Each program will include at least one full time professional position of "Project Screening Advocate" housed within the hospital system. The advocate works with communities and organizations within the surrounding area to develop and oversee the program according to the specific needs of each.
- The advocate will be responsible for providing culturally sensitive outreach and recruitment, assuring screening access and scheduling, monitoring screening compliance, and assuring prompt clinical evaluation and follow-up to positive testing.

#### Reimburse for colorectal cancer screening of uninsured Delawareans age 50 and older.

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
Establish a \$1.5 million annual allocation to colorectal cancer screening for the uninsured.	General Assembly, Executive Branch	Year 1	None	Proposed tobacco excise tax
2. Establish a system for billing and payment for colorectal cancer screenings whereby funds would be paid directly to health providers for reimbursable services based on Medicare rates.	DHSS	Year 1	Dependent on system developed	Proposed tobacco excise tax
3. Provide colorectal cancer screening for uninsured Delawareans age 50 and older that includes a comprehensive monitoring and evaluation program.	Dependent on system developed	Year 2 and ongoing	\$1.5 million annually	Proposed tobacco excise tax
Revise allocation based on actual costs and projections	General Assembly	Annually	None	

#### Points to Note:

- Population age 50-64 = 111,507
- Population uninsured age 50-64 = 18,220 based on estimates from the University of Delaware's Center for Applied Demography and Survey Research Delaware Demographic Database, 1994-1998 average uninsured population
- Screening = 1 colonoscopy every ten years
- Estimated cost per screen = \$500
- Assumes 80% compliance, all screenings done in next 5 years
- Cost estimates do not include changes in infrastructure

#### Case manage every Delawarean with an abnormal colorectal cancer screening test.

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
Establish a \$900,000 annual allocation for case management of Delawareans with abnormal colorectal cancer screening results.	General Assembly, Executive Branch	Year 1	None	Proposed tobacco excise tax
2. Establish a system for case managing every Delawarean with an abnormal colorectal cancer screening using current systems as models that includes a comprehensive monitoring and evaluation system.	DHSS	Year 1	To be deter- mined	Proposed tobacco excise tax
Begin case management system.	Dependent on system developed	Year 2 and ongoing	\$900,000 annually	Proposed tobacco excise tax
Revise allocation based on actual costs and projections.	General Assembly	Annually	None	

# WHATIFIHEN

80% of Delawareans age 50 and older received a colonoscopy and appropriate follow-up every 10 years?

Delaware would have the lowest colorectal cancer death rate in the country, decreasing by more than 60%.

(National Center for Health Statistics; Ransohoff and Sandler 2002; Coldiz 2000)

the gap in death rates between whites and minorities in Delaware would begin to close.



"After a pelvic sonogram, my internist and a radiologist showed me 20 tumors in my abdomen. I waited a week to be scheduled for surgery and another month for the procedure to take place. This was after I had had a complete physical three months before and was told I was in fine health. In Delaware, we need to update our diagnostic tools and recommend them to a patient, talk directly to the patient and educate them about alternatives. Sensitivity training should start at the front door." | Rebecca Wolhar, Wilmington.





## PROVIDE THE HIGHEST QUALITY OF CARE FOR EVERY DELAWAREAN DIAGNOSED WITH CANCER

The Council heard testimony from people with cancer. Their compelling stories detailed frustration with the overwhelming and fragmented health care system. A team approach that guides us on all levels, medically, emotionally and financially, can ease the burden and help us make informed choices. Every Delawarean also has the right to high-quality, compassionate health care that follows the latest cancer screening recommendations and treatment options. The difference can be a cancer found early and cured rather than one where delayed treatment leads to the cancer spreading and increasing the chance of death.

- Some Cancer Centers in the United States are taking a team approach to cancer care. In addition
  to oncologists and surgeons, the teams often include professionals like oncology nurses, case managers, social workers and dieticians.
- More than 600 cancer-related services are available throughout Delaware. The reality is many barriers hinder access to these resources. A case manager for every cancer patient would link patients and resources.
- Many Delawareans are already getting routine checkups. These visits must be used to encourage
  routine cancer screenings and promote prevention. A comprehensive evaluation of cancer screening practices will increase early detection.

Percent of Delawareans who have visited a doctor in the past year for a routine checkup

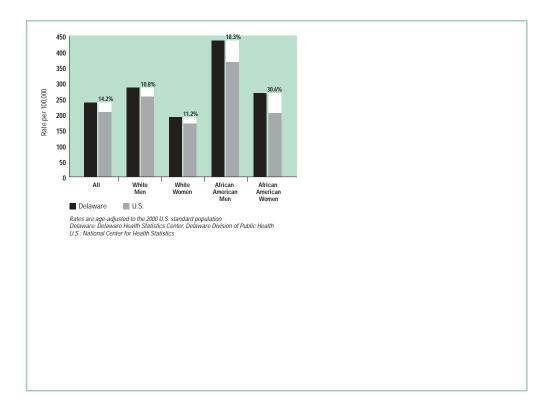
Age 45-54: 70.2% Age 55-64: 86.2%

(Behavioral Risk Factor Surveillance Survey 2000)

• On average, the cost of care in the first six months of treatment is 33% less when cancers are found in the early stage (in situ) instead of the late stage (distant). (Eddy 1990; Taplin, Barlow et al. 1995; Penberthy, Retchin et al. 1999)

## ARE SOME OF US MORE LIKELY TO BE AFFECTED BY THIS THAN OTHERS?

PERCENTAGE DIFFERENCE BETWEEN DELAWARE AND U.S. AGE-ADJUSTED ALL CANCER MORTALITY RATES\* BY SEX AND RACE, 1994-98



The rate at which people die from cancer in Delaware is consistently higher than the nation. This gap in cancer deaths can be attributed to the type of cancers, lack of screening and the need for improved access to state of the art care.

#### WHAT CAN BE DONE?

The Council recognizes that quality of care issues in all levels of cancer care must be addressed on an on-going basis and the recommendations that follow are first steps. It is the recommendation of the Advisory Council that the Permanent Council (see Implementation of Recommendations, Page 62) have a Medical Committee, led by oncologists, to oversee implementation of these and future recommendations to make Delaware a model for cancer care. The committee will require administrative support and should include professionals in a range of disciplines addressing cancer care such as pediatrics, surgery, dietetics, palliative care and social work.

Provide a care coordinator who is part of a statewide-integrated system to every person diagnosed with cancer in Delaware. Care coordinators will be culturally competent to overcome the language, ethnicity and gender barriers.

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
Establish a \$2 million annual allocation for the development of a core group of Cancer Care Coordinators to link patients with medical and support services. 25 coordinators statewide recommended.	General Assembly, Executive Branch	Year 1	None	Proposed tobacco excise tax
2. Define and oversee the development of the care coordinator program that includes a statewide system to link and maintain systems for multi-disciplinary care of all cancer patients.	Permanent Council – Medical Committee	Year 1 and ongoing	see Implementation recommend- ations	Delaware Health Fund, Proposed tobacco excise tax
Conduct care coordination program for all Delawareans diagnosed with cancer.	Permanent Council- Medical Committee	Year 2 and ongoing	\$2 million annually	Delaware Health Fund, Proposed tobacco excise tax

#### Assure insurance coverage for state of the art cancer clinical trials

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Amend Section 3559 G (a)(3)(c) of the Delaware Code and Regulation 69.505 A 3 to include cancer prevention trials.	General Assembly, Executive Branch	Year 1	None	
2. Encourage the involvement of all seven major Delaware health systems (Nanticoke, Beebe, BayHealth, Christiana Care, Veterans Hospital, A.I. duPont Hospital for Children and St. Francis) in the establishment of a statewide Cooperative Oncology Group in keeping with the American Cancer Society and the Coalition of National Cooperative Groups: A partnership for Cancer Clinical Trials.	Delaware Healthcare Association, Administration, DHSS, Medical Society of Delaware	Year 1	None	

Point to note:Recently passed legislation assures insurance coverage for treatment clinical trials. This recommendation adds prevention clinical trials to those covered services.

# Institute centralized credentialing reviews of medical practices by third party payors that includes cancer screening, prevention, early detection and treatment practices as well as ongoing provider education.

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
Obtain approval for centralized credentialing from     National Center for Quality     Assurance.	Permanent Council	Year 1	None	
Define and oversee the development and continuing quality of the credentialing program.	Permanent Council - Medical Committee	Year 1 and ongoing	see note below	
Develop and implement a comprehensive program, managed by a vendor selected through (Request for Proposal) process, that includes:     all data elements required by third party payors	Permanent Council- Medical Committee, con- tracted vendor, third-party payors	Year 1 and ongoing	\$210,000 annually	Third-party payors
all appropriate cancer screening, diagnosis and treatment data elements				
<ul> <li>education of medical providers and office staff</li> </ul>				
<ul> <li>practice reviews/ data collection</li> </ul>				
<ul> <li>development of practice specific recommendations</li> </ul>				
<ul> <li>individualized coaching for improvement</li> </ul>				
<ul> <li>evaluation and reporting of progress to Permanent Council</li> </ul>				

#### Point to note:

• Practices are currently evaluated by individual third party payors on the content of their records, but effective feedback on how to improve screening methods is lacking. Centralizing the review process would eliminate duplication of efforts and decrease costs. The educational feedback to the individual practices would be comprehensive in nature, tailored to their needs and focused on improving cancer-screening rates.

## Support training for physicians and other health care providers in symptom management and end of life care approaches.

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Promote and fund "Education for Physicians on End of Life Care" (EPEC) and "End of Life Nursing Education Consortium" (ELNEC) (existing programs). Two programs per county each year.	DHSS, Medical Society of Delaware	Year 2 and ongoing	\$1,800 annually	Proposed tobacco excise tax, Robert Wood Johnson Foundation
Establish physician and related health care professional accrediting based on EPEC program content.	DHSS, Medical Society of Delaware	Year 2	see note below	
3. Require that all patient advo- cates receive credentialing in pain management, palliative care and end of life care issues.	DHSS, health systems (see recommendation on care coordinators)	Year 2	see note below	Robert Wood Johnson Foundation
t4. Fund broad based community education programs related to end of life choices (to include long term care, palliative care and hospice care).	DHSS	Year 2	To be determined	

#### Points to note:

• EPEC and ELNEC are nationally recognized education programs that educate physicians and nurses in essential clinical competencies around end of life care. Existing efforts include Delaware End of Life Consortium, Christiana Care Health Systems and Delaware Hospice. This recommendation seeks to enhance existing programs. Coordination with existing Continuing Medical Education (CME) sources throughout Delaware could enhance education to the medical community.

## WHAT IF

Every person diagnosed with cancer in Delaware had a qualified case manager to make sure they had access to all the services they needed...

THEN differences in the death rates between whites and minorities would decline

 $\Gamma\!H\!E\!N$  many barriers to care could be eliminated

 $\Gamma\!H\!E\!N$  the quality of life for people with cancer would be better

THEN treatment outcomes would improve

## WHAT IF

Physicians improved their cancer screening practices...

THEN Cancer screening rates would increase

THEN follow-up on abnormal results would improve

THEN cancers would be diagnosed and treated earlier

THEN cancer death rates would decrease



# REIMBURSEMENT OF CANCER TREATMENT COSTS

"I was in the Screening for Life program. They paid for my mammogram and biopsy but nothing else. My radiation bill alone was \$10,000. It's like once you have cancer, they'll tell you you have it and then you're on your own. My husband also has cancer. I'm on disability and he's on social security. There's just no extra money for medical bills. This has been a financial tragedy for us. I don't know what we're going to do."

SHIRLEY MOORE, WILMINGTON.





#### PAY FOR CANCER TREATMENT FOR THE UNINSURED

275 Delawareans without health insurance will be diagnosed with cancer this year. (Delaware Division of Public Health, Delaware Cancer Registry, Delaware Division of Public Health; University of Delaware's Center for Applied Demography and Survey Research 1994-1998)

#### THE AVERAGE COST OF THE FIRST YEAR OF CANCER TREATMENT

(Eddy 1990; Taplin, Barlow et al. 1995; Penberthy, Retchin et al. 1999)

TYPE OF CANCER	STAGE OF DIAGNOSIS	AVG COST OF FIRST YEAR TREATMENT
Colorectal	Local	\$34,362
Colorectal	Distant	\$40,670
Breast	Local	\$20,348
Breast	Distant	\$34,396
Cervical	Local	\$30,304
Cervical	Distant	\$48,560

#### WHAT CAN BE DONE?

# Reimburse the cost of cancer treatment for every uninsured Delawarean diagnosed with cancer up until one year after diagnosis.

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
Establish a \$5.0 million annual allocation for cancer treatment of the uninsured	General Assembly Executive Branch	Year 1	None	Proposed tobacco excise tax
2. Establish a system for billing and payment for cancer treatment whereby funds would be paid directly to health providers for reimbursable services based on Medicare rates. Develop a comprehensive monitoring and evaluation program	DHSS	Year 1	To be determined	Proposed tobacco excise tax
Begin reimbursements for treatment for uninsured Delawareans diagnosed with cancer based on established system.	DHSS	Year 2	\$5.0 million annually	Proposed tobacco excise tax
Revise allocation based on actual costs and projections	General Assembly	Year 2 and annually	None	

#### Points to note:

- Billing and payment system to be determined and should take into consideration existing programs that could be built on or used as a model (e.g. Medical Society of Delaware's MEDNET).
- Estimates based on:
  - Medicare reimbursements for cancer care
  - 10% uninsured population
  - Current Delaware cancer incidence rates and stage at diagnosis
  - Costs for one year of treatment assumed to be twice the cost of six months of care



PROVIDE RELIABLE AND USEABLE CANCER INFORMATION

"I put off having my annual mammogram because we didn't have insurance at the time. I was persuaded to get one through Screening for Life. I was just two months late for it, but it showed a mass in my breast that turned out to be cancer. If I had not had the mammogram, it would've probably been too late for me. It was an aggressive tumor." | Nellie Foster, Dover.



#### PROVIDE RELIABLE AND USEABLE CANCER INFORMATION

Cancer is a complex disease. New information about causes, early detection and treatment is available to us every day. We need to have reliable and useful information in order to make healthy choices. The decisions we make today will affect Delaware's cancer rates in the future.

## ARE SOME OF US MORE LIKELY TO BE AFFECTED BY THIS THAN OTHERS?

Minority populations are less likely to get routine cancer screening tests. As education and income levels decrease, cancer screening rates also decrease. Cancer-related public education is inadequate to ensure individuals are able to make informed lifestyle and cancer care decisions. Education efforts must be carefully targeted to communities where cancer prevention can make the most difference.

#### PROPORTION OF DIFFERENT GROUPS EVER SCREENED FOR CANCER

(Center on an Aging Society, 2000)

	Prostate Cancer		Breast Cancer	Cervical Cancer		Colore Cance		Skin Cancer
	Men 50+	Women 40	)+	Women 40+	Adults 50+			All Adults
Screening Service	Exam (%)	Exam (%)	Mammogram (%)	Pap Test (%)	Blood Stool Test (%)	Digital Rectal Exam(%)	Proctoscopic Exam (%)	Exam (%)
ALL GENDER	84	87	80	91	48	57	36	21
Male	_	_	_	_	48	63	41	20
Female	_	_	_	_	48	52	32	22
RACE								
White	86	88	81	92	49	59	37	23
Black	80	83	75	90	40	48	28	11
INCOME								
\$20,000	80	79	71	86	42	49	30	16
\$55,000	88	94	88	96	56	65	42	27
RESIDENCE								
Urban	86	87	81	91	50	58	37	22
Rural	78	86	78	92	42	54	33	19
MARITAL STATUS								
Married	86	89	82	94	50	61	38	23
Not Married	80	83	76	88	44	51	32	18

#### WHAT CAN BE DONE?

Initiate and support statewide and district-level school health coordinating councils. The statewide council will serve as a model, resource and funding vehicle for the district councils.

DECDONICIDI E DA DEV			
RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
General Assembly	Year 1		
DOE, DHSS	Year 1	\$100,000 all Phase 1 activities	Proposed tobacco excise tax
	Year 1		
DOE with support of DHSS	Year 1		
DOE, DHSS	Year 1	Existing resources	
Statewide council	Year 2	\$100,000 all Phase 2 activities	Proposed tobacco excise tax, CDC grant
Statewide council	Year 2		
Statewide council, all dis- tricts	Years 3-4	\$195,000 all Phase 3 activities	Proposed tobacco excise tax, CDC grant
Statewide council	Year 3 and ongoing		
	DOE, DHSS  DOE, DHSS  DOE, DHSS  Statewide council  Statewide council  Statewide council, all districts	DOE, DHSS  Year 1  Year 1  DOE with support of DHSS  Year 1  DOE, DHSS  Year 1  Statewide council  Year 2  Statewide council  Year 2  Statewide council, all districts	DOE, DHSS  Year 1  \$100,000 all Phase 1 activities  Year 1  DOE with support of DHSS  Year 1  DOE, DHSS  Year 1  Existing resources  Statewide council  Year 2  \$100,000 all Phase 2 activities  Statewide council  Year 2  Statewide council  Year 3  Statewide council, all districts  Years 3-4  \$195,000 all Phase 3 activities

### Form a statewide, permanent alliance to coordinate and promote public education on cancer.

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
Solicit participation in the alliance of all stakeholders.	Permanent Council- Education Committee	Year 1	None	
Select an independent facilitator to assist the alliance in needs assessment, planning, organizational structure and program focus	Permanent Council, Alliance	Year 1	\$190,000 all activities Tasks 2 through 6.	Proposed tobacco excise tax
3. Develop a unified mission to provide consumer information and education on prevention, screening, detection and treatment, best practices for care and available resources.	Alliance, facilitator	Year 1		
4. Investigate methods to reach populations at higher risk for cancer with screening, early detection and prevention messages	Alliance	Year 2		
5. Collect and integrate data on public education in cancer	Alliance, facilitator	Year 2		
6. Conduct a statewide summit to review findings and opportunities for integration, collaboration and unique product development	Alliance	Year 3		

#### Point to note:

<sup>• \$190,000</sup> estimate includes materials and operational costs to support the needs assessment, planning, data collection and integration, evaluation of media formats and messages, and administrative costs for sustaining this initiative. (Brownson and Ross 1999)





REDUCE ENVIRONMENTAL **CANCER THREATS** 

"Justin was diagnosed with a malignant brain tumor in July of 1998, 4 weeks before he was to start his freshman year at Penn State. He died two years later. It seemed as though I was holding my infant son once again as I looked down at his face and half closed eyes. I made a promise to him that we would find out what caused his cancer. That promise rings in my ears...to find the answers to questions he never wanted another parent to have to ask. Why did my child get cancer and why did he have to die?" MARY ELLEN NANTAIS OF NEWARK WHOSE SON, JUSTIN,

DIED OF CANCER IN 2000 AT AGE 19.



## REDUCE THE THREAT OF CANCER FROM THE ENVIRONMENT.

Exposures to cancer causing substances can occur anywhere—including our home, our workplace, during our commutes, the buildings we enter and where we spend time outside. If we know more about our environment, we can make healthy decisions and good policies. To guide us, it is also important that we collect data to have a better understanding of environmental links to cancer.

#### WHAT CAN BE DONE?

The Council recognizes that carcinogens can be present in the air we breathe, the water we drink, the food we eat, things that touch our skin and many other places. The decision to address the following issues on a limited basis was based on the amount of reliable information that is available and the potential to affect a change in exposure levels. It is the recommendation of the Advisory Council that the Permanent Council have an environment committee to oversee implementation of these recommendations and that carcinogens from water, food and other sources be included in future recommendations on a more comprehensive basis.

Reduce exposures to carcinogenic substances in the ambient environment.  The following specific tasks and activities should be included:						
TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES		
A. Related to Delaware Air						
A1. Conduct specialized ambient air quality monitoring to determine actual concentrations of air toxins in Delaware.	DNREC	Year 1	\$300,000 plus \$300,000 exist- ing resources	Proposed tobacco excise tax		
A2. Evaluate the types of cancers associated with those substances found at elevated levels and compare to those cancers for which Delaware is elevated in incidence and mortality (link databases).	DNREC, DHSS	Year 2	Existing resources			
A3. Notify the public of past and current levels of carcinogenic substances that are monitored in Delaware.	DNREC, Permanent Council	Year 2	Existing resources			
A4. Acting on the information from monitoring, develop and implement strategies to reduce air contamination from those sources.	DNREC, Permanent Council	Year 2 and Ongoing	Existing resources			

Reduce exposures to carc	inogenic substances in the	he ambient environ	ment.	
TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
B. Related to Delaware Drinking	Water			
B1. Expand monitoring of state's shallow aquifers for pesticides by increasing the number of pesticides/herbicides and their degradants analyzed.	DDA, DHSS, DNREC		\$80,000 annual- ly to support DDA monitor- ing network	US EPA
B2. Initate screening of all public water systems using shallow wells. Continue monitoring of public water systems and private shallow wells near known hazardous waste sites for cancer causing substances not currently regulated by the US EPA or the state.	DHSS, DNREC	Year 1 and ongoing	\$400,000 annually	Hazardous Substance Control Act (HSCA),Proposed tobacco excise tax, Increase fees for services to public water systems
B3. Evaluate the types of cancers associated with those substances found at elevated levels and compare to those cancers for which Delaware is elevated in incidence and mortality.	DHSS	Year 2 and ongoing	Existing resources	
B4. Notify the public of past and current levels of carcinogenic substances that are monitored in Delaware.	DHSS, Permanent Council	Year 2 and ongoing	Existing resources	
B5. Acting on the information from monitoring, develop and implement strategies to reduce water contamination from those sources.	DHSS, Permanent Council	Year 2 and ongoing	Existing resources	N/A
C. Related to Delaware Waterwa	ys			
C1. Increase location, frequency, and number of fish sampled, from 20 total samples to 40 total samples annually.	DNREC, DHSS	Years 1-3	\$50,000 per year	Proposed tobacco excise tax
C2. Determine the level of awareness and actual compliance rates with fish advisory information and develop recommendations for improvement.	DNREC, DHSS	Years 1 and 2	\$10,000 per year	Proposed tobacco excise tax
C3. Conduct an education/awareness campaign related to C2 above.	DNREC, DHSS	Years 2 and 3	\$35,000 per year	Proposed tobacco excise tax
C4. Enhance on-site advisory information and warnings to include postings with metal and Tyvek signs, tamper resistant hardware, bilingual signs, and related literature.	DNREC DHSS	Years 1-3	\$30,000 per year	Proposed tobacco excise tax

## Coordinate with federal OSHA to reduce workplace carcinogenic risk and exposure.

0 1				
TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Establish full cooperative agreement with federal OSHA leading to the creation of an Office of Occupational Health to monitor, investigate, and enforce workplace OSHA violations and identify populations at risk from occupational exposure to carcinogens intitially, but with intent to extend to other toxic hazards	General Assembly, Executive Branch	Year 1	\$400,000, (Year 1) \$250,000 (Year 2 and on)	Proposed tobacco excise tax
Obtain exposure data for exposures to Delaware work-place carcinogens from OSHA.	Office of Occupational Health	Year 1		
3. Review federal OSHA requirements limiting exposure from carcinogens and determine if there are gaps relevant to DE that need to be addressed regarding employee protection.	Office of Occupational Health	Year 1		
4. Identify high-risk workers by reviewing the Toxic Release Inventory (TRI) data and targeting occupations not covered by OSHA at high risk for cancer.	Office of Occupational Health	Year 2		
5. Implement educational, regulatory and "right-to-know" programs to reduce exposure.	Office of Occupational Health	Years 3-4	\$50,000 annually	Proposed tobacco excise tax

### Reduce exposure to carcinogens in the indoor environment The following specific tasks and activities should be included:

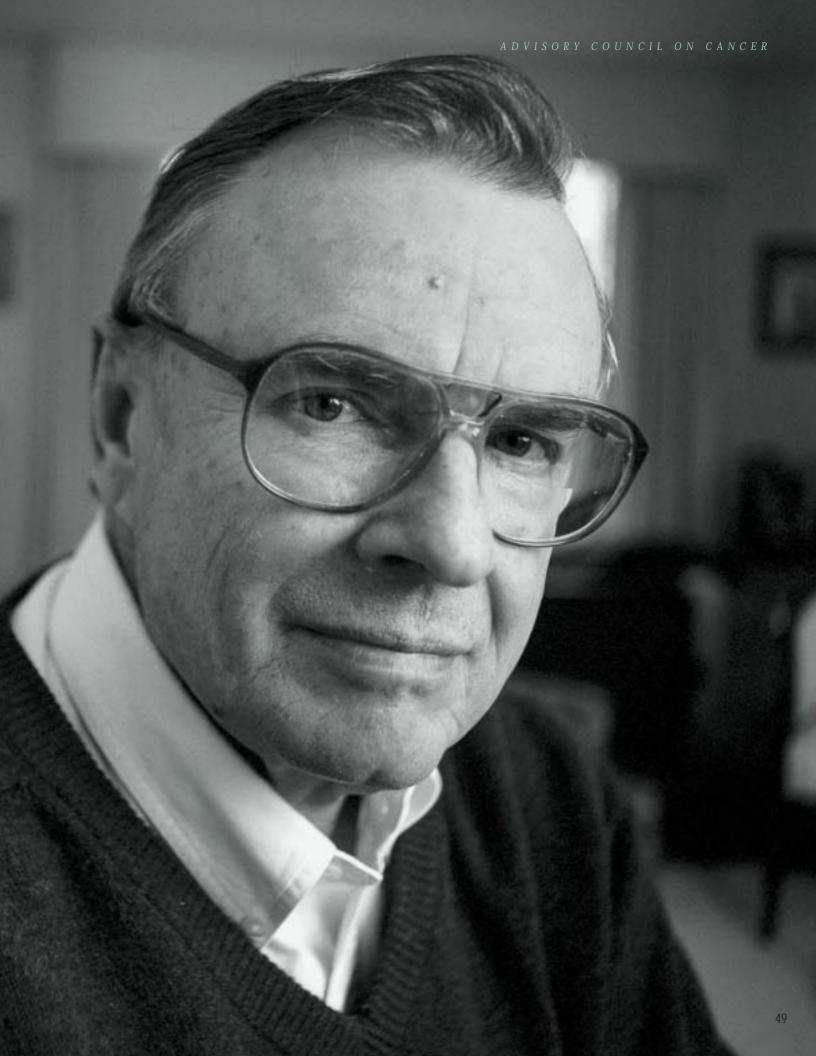
TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
Create and promote new initiative to increase radon testing and provide financial assistance for remediation to low-income homeowners.	DHSS	Year 1 and Ongoing	\$75,000 annually	Delaware Health Fund
Require radon testing in all residential real estate transfers (model after lead testing requirements).	General Assembly	Year 1		
3. Create industry incentives (e.g., interest-free loans) for dry-cleaners to eliminate the use of cancer causing solvents.	DEDO, DNREC	Years 2-5	To be determined	DEDO Strategic fund
4. Develop and maintain a broad-based public education campaign based on findings from the national Total Exposure Assessment Methodology (TEAM) studies. (Research Triangle Institute 1996)	DNREC, DHSS	Year 1 and ongoing	\$80,000 (Year 1) \$50,000 (Years 2 on)	Proposed Tobacco Excise Tax



INCREASE OUR KNOWLEDGE OF CANCER

"As a colon cancer survivor, I know firsthand that improved standards are needed. In my case, a large tumor in the cecum was not detected by colonoscopic exam." | Jerry Broussard, Wilmington, colon cancer survivor.





## INCREASE OUR KNOWLEDGE ABOUT CANCER INCLUDING ENVIRONMENTAL CAUSES

If we are to make sound decisions about controlling cancer in Delaware we must have reliable and complete information. Data can tell us about what we are doing well and where improvements are necessary. Even though we are a state with one of the most complete cancer registries in the nation, there are still improvements to be made. Collecting data is only the beginning - it is meaningless if we don't use it to target our efforts and use information to make real and lasting change.

## ARE SOME OF US MORE LIKELY TO BE AFFECTED BY THIS THAN OTHERS?

Without data and information, there would be no way of demonstrating that there are some of us more affected by cancer than others. While we often think of these differences in terms of race and ethnicity, we also know that a heavier burden falls on those of us with lower incomes, less education, and no health insurance.

#### WHAT CAN BE DONE?

Estimate the number of cancers that can be prevented and the number of deaths that can be avoided by primary prevention and early detection. Prioritize our common and preventable cancers.

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Collect data on known/sus- pected risk factors and calculate the number of preventable cancer cases and deaths, by gender, race, and age group, for each risk factor.	DHSS, Permanent Council	Year 1	\$50,000	Proposed Tobacco Excise Tax
Collect data on cancer diagnosis by stage and calculate the number of preventable cancer deaths, by gender, race, and age group, with earlier detection.	DHSS, Permanent Council	Year 1	\$50,000	Proposed Tobacco Excise Tax
3. Summarize and distribute results to improve program planning and healthy lifestyle choices.	DHSS, Permanent Council	Year 2	\$25,000	Proposed Tobacco Excise Tax

## Improve the collection and reporting of cancer incidence and mortality data.

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Amend the Cancer Control Act to extend the time inter- val within which a newly diagnosed cancer case must be reported to DPH to 180 days, consistent with standards of the American College of Surgeons.	General Assembly	Year 1	None	
Enforce reporting require- ments. Impose fines for non-reporting.	DHSS	Year 1	None	
3. Increase information collected by the cancer registry including demographics, occupational history, and exposures to certain risks.	DHSS	Year 2 and ongoing	\$300,000 annually	Proposed Tobacco excise tax
Improve reporting on death certificates of the cause of death by educating physicians on proper procedure.	DHSS	Year 1 and ongoing	\$20,000 annually	Proposed tobacco excise tax
5. Introduce and pass legislation requiring hospitals to staff their registries with a certified tumor registrar.	General Assembly	Year 1	None	
Provide certification training and annual continuing edu- cation for tumor registrars.	DHSS	Year 1 and ongoing	Existing resources	
7. Reclassify the Director position of Delaware Cancer Registry to a higher pay-grade.	DHSS	Year 2	Existing resources	
Publish report annually that integrates most recent cancer incidence, mortality, and risk behavior data.	DHSS	Year 1 and ongoing	Existing resources	
9. Fully staff the Delaware Cancer Registry and assure appropriate continuing education.	DHSS	Year 1 and ongoing	\$40,000 annually	CDC grant Delaware Health Fund

Improve the collection and reporting of cancer incidence and mortality data.  (Continued)				
TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
10. Expand population-based survey of present and past tobacco use and exposure to environmental tobacco smoke (ETS). Report statisti-	DHSS	Year 2	\$100,000	Proposed tobacco excise tax
cally valid results by age, race, income, educational level, occupation, gender, and zip code.				
11. Develop a public education campaign on cancer rates and their age-adjustment to the 2000 U.S. standard population.	DHSS, Governor's office	Year 1	Existing resources	
12. Evaluate the ability to standardize race and ethnicity data collection across cancer related data sets.	DHSS	Year 2	\$25,000	Proposed tobacco excise tax
13. Evaluate the ability to match cancer incidence and mortality records, including special software, and develop matching capabilities.	DHSS	Year 2	\$25,000	Proposed tobacco excise tax

## Conduct a survey to examine the importance of past exposures to today's cancer rates.

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Conduct a retrospective survey of individuals with cancer or family members of cancer patients to collect information on family history, occupation, lifestyle, diet, exercise, migration, etc. (include only those cancers for which the state is elevated in incidence or mortality). Obtain data necessary to determine which environmental factors may contribute to Delaware's heightened cancer rates.	DHSS	Years 1-3	\$250,000	Proposed tobacco excise tax
Analyze results and develop appropriate control strategies.	DHSS	Year 3	\$50,000	Proposed tobacco excise tax

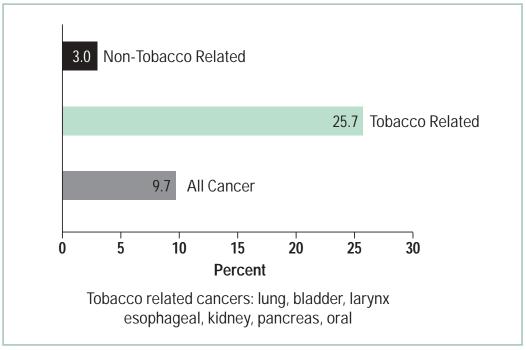




#### REDUCE TOBACCO USE AND EXPOSURE

Tobacco related cancers account for more than one third of all the cancers in Delaware. Delawareans smoke at a higher rate than people in 22 other states. Tobacco smoke affects smokers and non-smokers and cancer is only one of many health problems caused by tobacco. Delaware has recently increased its tobacco control spending by more than five times, but there are still actions we can take that will help protect us from the effects of tobacco.

#### PERCENTAGE INCREASE OF DELAWARE CANCER AGE-ADJUSTED INCIDENCE VS. U.S. ESTIMATE, 1994-1998



Delaware: Delaware Cancer Registry, Delaware Division of Public Health; U.S.: Surveillance, Epidemiology and End Results (SEER) Program, National Cancer Institute.

- If not for lung cancer, the overall cancer death rate in the United States would have declined by 14% since 1950. Instead, it has increased 22%. (Surveillance, Epidemiology and End Results (SEER) Program, National Cancer Institute.)
- The death rate from lung cancer has increased only slightly overall, but is increasing more rapidly among women. In recent years, lung has surpassed breast as the leading cause of cancer death among women. (National Center for Health Statistics)
- Delaware has the 32nd lowest cigarette tax in the nation. (Campaign for Tobacco-Free Kids 2001)

#### WHAT CAN BE DONE?

# At a minimum, fund comprehensive statewide tobacco control activities at \$8.6 million (CDC recommended minimum)

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
Educate members of the Delaware Health Fund Advisory Committee regarding the need for adequate funding in order to achieve the desired results.	IMPACT	Year 1 and ongoing	None	
Create increased public demand for a fully funded tobacco control program using polling and public awareness activities.	IMPACT	Year 1 and ongoing	\$25,000	Robert Wood Johnson Foundation
Advocate for Health Fund allocations at CDC recommended funding levels.	IMPACT, DHFAC	Annually	None	
Report to the public on the use of tobacco funds.	All agencies receiving funds	Annually	Existing funds	
5. Fund tobacco control activities at the CDC minimum recommendations.	DHFAC, General Assembly	Year 1 and ongoing	see note below	Delaware Health Fund

#### Point to note:

<sup>•</sup> An additional \$3.6 million added to existing resources is needed for the CDC recommended minimum funding of \$8.6 million ("Best Practices for Comprehensive Tobacco Control Programs" 2001). Recommended uses for this funding are outlined in the remaining tobacco control recommendations.

## Strengthen, expand, and enforce Delaware's Clean Indoor Act to include public places and workspace environments.

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Advocate passage of a strong anti-exposure to Environmental Tobacco Smoke (ETS) law, Senate Bill # 99 as originally written (An Act to Amend Title 16, Delaware Code Relating to the Clean Indoor Air Act, 2001).	General Assembly, Executive Branch	Year 1	None	
2. Mobilize the support of governmental offices and other resources in support of relevant data gathering and dissemination.	Executive Branch, DHSS	Year 1	None	
Continue ETS media and educational campaigns.	DHSS	Year 1 and ongoing	Existing resources	
4. Continue grassroots support efforts begun in 2001.	IMPACT, Volunteer Groups	Year 1	None	
5. Begin public polling to assess public support for proposed legislation.	IMPACT, Campaign for Tobacco Free Kids	Year 1	\$50,000-\$75,000	Campaign for Tobacco-free Kids
Communicate with those opposed to new legislation to assure correct information and understanding.	IMPACT, Concerned Health Organizations	Year 1	None	
7. Upon passage, enforce law.	DHSS	Ongoing after passage	None*	

#### Points to Note:

- If the original version of Senate Bill 99 is passed, there will be little or no additional enforcement costs. If a bill requiring
  physical or mechanical separation barriers is passed, enforcement could cost up to \$500,000 more annually.
- Reducing exposure to secondhand smoke will positively influence all Delawareans. Recent national research suggests that exposure to secondhand smoke is as toxic, if not more toxic, than smoking itself.
- Senate Bill 99 has passed the Senate and is now being considered by the House. While there is clear evidence of public support for the legislation, there is also strong opposition and misinformation suggesting its passage will have a negative impact on select businesses. Extensive experiential data from other states concludes that this would not occur and can be obtained from the Division of Public Health.
- Resources used to formulate the recommendation: (Hopkins, Husten et al. 2001) (The Center for Social Gerontology 2001)

# Strongly endorse, coordinate and implement the action plan recommendations presented in "A Plan for A Tobacco Free Delaware"

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
Increase visibility of support for current plan actions/activ- ities. (IMPACT Delaware Tobacco Prevention Coalition 1999)	General Assembly, Executive Branch	Year 1 and ongoing	None	
Conduct activities outlined in the plan.	IMPACT, DHSS	Year 1 and ongoing	See note below	Delaware Health Fund
Continue process, impact and outcome evaluation of plan goals and objectives.	IMPACT, DHSS	Year 1 and ongoing	Existing resources	

#### Points to Note:

- The Council seeks to verify, acknowledge and support the solid tobacco control activities that have occurred and continue to occur. These efforts are consistent with the Council's agenda.
- Cost: To complete these activities, the CDC minimum recommended funding of an additional \$3.6 million to existing resources would be needed and is outlined in the first tobacco control recommendation ("Best Practices for Comprehensive Tobacco Control Programs" 2001)

## Formally adopt, implement and enforce the CDC model policy for tobacco control in all Delaware schools.

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
Re-educate school leadership regarding the content and merits of the CDC model school policy     ("A Coordinated School Health Program: The CDC Eight Component Model of School Health Programs" 2001).	IMPACT, DHSS, DOE	Year 1	Existing staff and resources	
2. Obtain administration's support for model policy adoption.	IMPACT	Year 1	None	
3. Draft Legislation requiring model adoption.	IMPACT, General Assembly	Year 1	None	
Implement the model (including education and enforcement components).	IMPACT, DOE, DHSS, local schools	Year 1	\$100,000	Delaware Health Fund

#### Point to Note:

• An existing federal mandate prohibits the use of tobacco products at any time on properties that serve children and receive federal funds. Yet daily violations by staff, visitors and students continue to be visible.

## Expand and sustain a comprehensive public awareness campaign on the health risks of tobacco use and support resources available to help quit smoking.

The following specific tasks and activities should be included:

Conduct a high profile media campaign	DHSS	Ongoing	\$1.2 million plus \$1.3 million of existing resources	Delaware Health Fund, Proposed tobacco excise tax
Maintain and enhance integrated cessation services.	DHSS	Ongoing	\$1.05 million plus \$450,000 of existing resources	Delaware Health Fund, Proposed tobacco excise tax
3. Formulate and coordinate consistent messages to be delivered by all stakeholders (materials development).	Permanent Council- Education Committee	Ongoing	\$250,000	Delaware Health Fund, Proposed tobacco excise tax
4. Significantly expand Quitline services	DHSS	Ongoing	See cessation costs above	

#### Points to Note:

- ullet As proven interventions become available, cessation services specifically targeting youth and young adults should be expanded.
- Resources used to formulate the recommendation: (Hopkins, Husten et al. 2001) (Healthy Delaware 2010)

# Increase the Delaware excise tax on tobacco products to \$0.74 and seek to identify other potential funding sources to support tobacco and cancer control efforts

The following specific tasks and activities should be included:

Draft legislation to increase existing excise tax by \$0.50 per pack.	IMPACT, Legislative con- sultants	Year 1	None	
Seek legislative and administrative support, identify sponsor for bill.	IMPACT, Health lobbyists	Year 1	None	
3. Ensure that funds are directed to the Delaware Health Fund with major portion going to tobacco control, cancer control, and other chronic diseases.	Executive Branch, IMPACT, Legislative sponsors	Year 1	None	
4. Conduct community polling.	Campaign for Tobacco Free Kids(CFTFK)	Year 1	\$75,000	Robert Wood Johnson, CFTFK, AHA, ALA, ACS
5. Implement grassroots awareness/support campaign.	IMPACT	Year 1	\$250,000	same
Conduct public awareness campaign.	IMPACT, Permanent Council, DHSS	Year 1	\$200,000	same
7. Educate General Assembly.	IMPACT, lobbyists	Year 1	\$400,000 PR/lobbying	
8. Pass legislation increasing tax.	General Assembly	Year 2		

#### Point to Note:

• Delaware's tobacco excise tax is currently \$0.24, lowest in the region and 32nd lowest nationally. The recommended \$0.50 increase would generate an additional \$49.0 million annually. Delaware has not increased its tobacco excise tax in more than ten years. (Campaign for Tobacco-Free Kids 2001)

# WHATIFIHEN

30 years ago, no one in Delaware smoked?

instead of our lung cancer incidence rate today being 10% above national estimate, it would be 12% below the national estimate.

(Delaware: Delaware Cancer Registry, Delaware Division of Public Health; US: Surveillance, Epidemiology and End Results (SEER) Program, National Cancer Institute)

# WHATIFIHEN

Delaware's excise tax were increased by \$0.50 per pack?

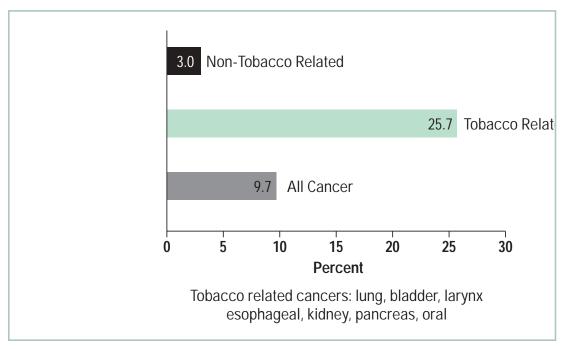
- 4,200 fewer Delaware kids would start smoking
- 1,300 Delaware kids would be saved from a smoking death as an adult
- 4,000 fewer Delaware adults would smoke
- \$83.4 million dollars in long-term health care costs would be saved
- \$49 million dollars each year in revenue would be generated

(Source: Campaign for Tobacco Free Kids, 2001)

## ELIMINATE THE UNEQUAL CANCER BURDEN

Our race, ethnicity, gender, where we live, income and whether we have insurance affect our chances of getting cancer, how early it is diagnosed and whether we live or die.

## DELAWARE FIVE YEAR RACE ADJUSTED INCIDENCE AND MORTALITY RATES PER 100,000, 1995-1999



(Incidence: Delaware Cancer Registry, Delaware Division of Public Health. Mortality: Delaware Health Statistics Center, Delaware Division of Public Health)

Note: 1999 incidence data are provisional. Rates are age-adjusted to 2000 U.S. standard population.

• White residents are more likely to have cancer diagnosed at an earlier stage than are African American residents (49% diagnosed in early stages for white, 43% for African American).

Note: 1999 data are provisional.

Source: Delaware Cancer Registry, Delaware Division of Public Health)

 Residents in Sussex County are less likely to have cancer diagnosed at an earlier stage than are residents in Kent County and New Castle County.
 Source: Same as above.

#### WHAT CAN BE DONE?

Some Delawareans are more likely to get and die from cancer and the differences are often astounding. The Council recognized this as a significant problem and put special emphasis on ways to eliminate these differences. While the following recommendation is the only one that specifically targets this problem, it is also an integral part of nearly every other recommendation in this report. Efforts must be made on all levels to realize change.

# Compile and analyze existing data on health disparities and cancer into a report and inform through a public education campaign. The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Analyze data on minorities associated with poor health outcomes for cancer overall and for breast, lung, colorectal, and prostate cancers specifically.	DPH, University affiliated centers, Permanent Council	Year 1	\$20,000	Proposed tobacco excise tax
2. Analyze trends in disparities related to societal, policy or system level changes that may affect whether certain groups get cancer or die from cancer.	DPH, University affiliated centers, Permanent Council	Year 1	\$20,000	Proposed tobacco excise tax
3. Develop a fact sheet with action steps and a public education campaign that correlates with the demographic, health, behavior and social data collected above. Campaign would discuss how to decrease cancer incidence and mortality in DE among minorities and highrisk groups.	DPH, University affiliated centers, Permanent Council	Year 2	\$10,000	Proposed tobacco excise tax



IMPLEMENTATION OF RECOMMENDATIONS

"The recommendations of this Council will be a powerful force for change. We know what needs to be done, who should do it and where we go from here. Delaware has the opportunity to take action and make positive changes in the lives of all its citizens."

| WILLIAM W. BOWSER, ESQUIRE, OF WILMINGTON, DE, COUNCIL CHAIR WHOSE SON, MICHAEL, IS A

LEUKEMIA SURVIVOR.



#### IMPLEMENTATION OF RECOMMENDATIONS

The recommendations provided in this report provide a blueprint for action. If implemented, fewer people will die from cancer in Delaware, more people will get quality cancer care, and eventually fewer people will get cancer. However, none of this will happen unless the state institutionalizes a process to continue the work of the Council.

#### WHAT CAN BE DONE?

Create and maintain a Permanent Council, managed by a neutral party, that reports directly to the Governor to oversee implementation of the recommendations and comprehensive cancer control planning. The Council should have Medical, Environment, Research, Policy and Education committees that continually evaluate and work to improve cancer care and cancer related issues in Delaware.

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
Re-constitute and make permanent the Delaware Advisory Council on Cancer Incidence and Mortality which shall report directly to the Governor	General Assembly	Year 1	None	
2. Disband DHSS's Advisory Council on Cancer Control as authorized in current legisla- tion and replace with perma- nent Council listed in Step 1.	General Assembly	Year 1	None	
3. Allocate resources for ongoing administrative support to the Council, including one full time staff person with the sole responsibility of the coordination of this group and its committees.	General Assembly	Year 1 and ongoing	\$100,000 annually	Proposed tobacco excise tax
4. Solicit participation of all stakeholders for the general Council. Clear definition of member expectations, roles and responsibilities should be provided.	Staff person, neutral party manager	Year 1	\$25,000-Steps 4-6	Proposed tobacco excise tax

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
5. Develop a structure and charge for the Permanent Council and each individual committee.	Staff person, Permanent Council	Year 1		
6. Establish the individual committees, Medical, Environment, Research, Policy and Education. Experts in the respective field should lead each committee and clear definition of member expectations should be provided.	Staff person, Permanent Council	Year 1		
7. Oversee implementation of the current recommendations and any future recommendations in coordination with the planning process.	Staff person, Permanent Council and Committees	Year 1 and ongoing		
Coordinate an annual conference on the status of cancer in Delaware.	Permanent Council	Year 2 and annually	To be determined	
9. Develop an annual report to the Governor and Legislature on the status of current recommendations and the comprehensive cancer control plan and make additional recommendations as necessary.	Permanent Council	Year 2 and annually		

# Develop and implement a state cancer control and prevention plan. The plan should be based on CDC guidelines and involve multiple stakeholders with assigned responsibilities.

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
Develop planning process     that incorporates recommendations of the Delaware     Advisory Council on Cancer Incidence and Mortality.	Staff Person, Permanent Council	Year 1	\$100,000 all activities	Proposed tobacco excise tax
2. Fund implementation of the plan.	General Assembly	Year 1		
4. Monitor progress, give advice of needs and resources in DE, and assist with grants or fund development.	Permanent Council	Year 2 and ongoing		
5. Assign specific roles and accountabilities of private, non-profit, and government entities involved in implementation.	See Above	Year 2	N/A	
Publish the plan's development, implementation, and outcomes in the annual cancer report.	Permanent Council, DPH	Year 3 and ongoing		

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